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**Supreme Court of the United States**

October Term, 1989

LOUIS SULLIVAN,  
SECRETARY OF HEALTH AND HUMAN SERVICES,  
*Petitioner,*

v.

BRIAN ZEBLEY, JOSEPH LOVE, JR., et al.,  
*Respondents.*

ON WRIT OF CERTIORARI TO THE  
UNITED STATES COURT OF APPEALS  
FOR THE THIRD CIRCUIT

**BRIEF FOR THE AMICI CURIAE  
IN SUPPORT OF RESPONDENTS**

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DOWN SYNDROME TODAY

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## SUMMARY OF ARGUMENT

In order to effectuate its intent to provide financial assistance to disabled children in low-income families who are "certainly among the most disadvantaged of all Americans,"<sup>1</sup> Congress mandated that a child be eligible for Supplemental Security Income ("SSI") if he or she meets the income requirements and is disabled by "any medically determinable physical or mental impairment of comparable severity" to one that would render an adult eligible for SSI benefits.<sup>2</sup>

Despite this clear statutory mandate, the Secretary of Health and Human Services ("Secretary") has adopted by regulation two very different processes for determining disability of SSI applicants, depending on whether the

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1. H.R. Rep. No. 231, 92nd Cong., 2d Sess. 1, 147-48, reprinted in 1972 U.S. Code Cong. & Admin. News 4989, 5133-34.
  2. 42 U.S.C. § 1382c(a)(3)(A) (emphasis added).

applicant is a child or an adult. In blatant disregard of Congressional language and intent, the process applied to children is dramatically more restrictive than that applied to adults.

For adults, the Secretary engages in a comprehensive, two-tiered process. That process begins with an abbreviated approach, designed for administrative convenience, which compares an adult's impairments to the Secretary's Listing of Impairments ("Listings").<sup>3</sup> If the adult's impairments do not "meet or equal" those within the Listings, the Secretary proceeds to the second tier of the

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3. The Listing of Impairments, 20 C.F.R. Part 404, Subpart P, App. 1 (Jt. App. at 115-235) is a catalog of medical findings descriptive of certain diseases and disabilities. The Listings are divided into two parts. Part A is applied to adults 18 years of age and older and "may also be applied in evaluating impairments in persons under age 18 if the disease processes have a similar effect on adults and younger persons." 20 C.F.R. § 416.925(b)(1). Part B is applied solely to persons under the age of 18. 20 C.F.R. § 416.925(b)(2).

process -- an assessment of residual functional capacity ("RFC") -- which entails an evaluation, on an individualized basis, of the full effect of the claimant's functional limitations.

The Secretary's two-tiered process for determining disability in adult claimants stems from the recognition that evaluating an individual's impairments solely in terms of the Listings is insufficient. The Listings are not -- and cannot ever be -- sufficiently comprehensive to enable the Secretary to consider combinations of impairments, the impact of impairments on a claimant's ability to function, the interaction of various impairments, or subjective factors, such as pain, dizziness, or side effects of medication. Accordingly, the Secretary's evaluation process for adults includes both an abbreviated, Listings-based approach and an individualized assessment of functioning if the individual's impairments do not meet or equal those within the Listings. The Secretary has thus implic-

itly conceded that the Listings -- by themselves -- do not work in all cases.

In sharp contrast to the process for adults stands the process for children, which begins and ends with a determination of whether the child's impairments can be pigeonholed into the Listings. If the child's impairments "meet or equal" those within the Listings, he or she gets benefits; if they do not, he or she is denied benefits -- without any consideration whatsoever of the effects of the impairments on the child's functional abilities, the combined effect of multiple impairments, or subjective factors. Thus, unlike the evaluation process accorded adults, there is no opportunity for children to demonstrate that their functional limitations render them disabled.

A unanimous panel of the United States Court of Appeals for the Third Circuit struck down the Secretary's process for determining disability in children as flatly inconsistent with the statute, holding that the regulations

"do not provide for [an] individualized assessment for children, although they are entitled by statute to receive benefits if suffering from 'any' impairment of 'comparable severity'" to one that would entitle an adult claimant to benefits. Zebley v. Bowen, 855 F.2d 67, 73 (3d Cir. 1988). The court of appeals determined that the Listings "do not purport to be an exhaustive compilation of medical conditions which could impair functioning to the extent necessary to satisfy the statutory standard for disability," yet only adults are given the opportunity to demonstrate disability through a further individualized, functional assessment. Id. at 73. "Persuaded that in the statutory directive that 'any' impairment may be disabling if severe enough, Congress has clearly expressed an intention that children be given the opportunity for individual evaluations comparable to the residual functional capacity assessment for adults," the court held that "an individualized determination of the degree of functional incapacitation is required by statute during



the disability determination process for children." Id. at 76.

Amici Curiae urge this Court to affirm the decision of the court of appeals.

#### INTERESTS OF AMICI CURIAE

Amici Curiae represent children with severe and often debilitating handicaps who have been or may in the future be denied SSI benefits because of the Secretary's truncated and formalistic approach. Amici are deeply concerned that disabled children receive a fair opportunity to obtain disability benefits. Amici, which consist of almost every major non-profit disability group in Pennsylvania, are as follows:

Pennsylvania Protection and Advocacy is an organization designated by the Governor of Pennsylvania under the Developmentally Disabled Assistance and Bill of Rights Act of 1984, P.L. 98-527, 98 Stat. 2662, 42 U.S.C. § 6000 et seq., and the Protection and Advocacy for Mentally Ill Individuals Act of

1986, P.L. 99-319, 100 Stat. 478, 42 U.S.C. § 10801 et seq., to safeguard and advance the rights of persons with physical, developmental, and mental disabilities.

The Mental Health Association in Pennsylvania is a statewide organization that has, for the past thirty-five years, developed and mobilized broad-based citizen support for rights protection and improved care and treatment for adults and children who have mental illnesses.

The Pennsylvania Mental Health Consumers' Association is an organization of consumers of mental health services, including children, across the Commonwealth of Pennsylvania.

The Pennsylvania Coalition of Citizens with Disabilities is a statewide, cross-disability, consumer-directed and oriented organization devoted to the integration of all citizens with disabilities into the mainstream of life, and the development of comprehensive service systems to include all citizens.



The Developmental Disabilities Planning Council of the Commonwealth of Pennsylvania is a council federally-mandated under the Developmentally Disabled Assistance and Bill of Rights Act that addresses gaps in policy and service delivery for persons with developmental disabilities.

The Pennsylvania Association for Retarded Citizens is a statewide organization committed to creating full opportunities for persons with mental retardation.

The Pennsylvania Association for Children and Adults with Learning Disabilities is a statewide organization of parents and professionals dedicated to the attainment of appropriate human service programs for persons with disabilities.

The Association for Children and Adults With Learning Disabilities is a national organization dedicated to increasing the quality of life and expanding appropriate services for individuals with learning disabilities.

The Spina Bifida Coalition of Pennsylvania is a coalition of seven associations located throughout Pennsylvania that are dedicated to assisting individuals with spina bifida.

The Prader-Willi Syndrome Association of Pennsylvania is an organization dedicated to assisting persons with Prader-Willi Syndrome, along with their families.

The Pennsylvania Tourette Syndrome Association, an agency affiliated with the National Tourette Syndrome Association, was created to serve the needs of Pennsylvania citizens with Tourette Syndrome.

United Cerebral Palsy Association of Pennsylvania represents nineteen affiliate agencies throughout Pennsylvania that serve over 11,000 children and adults with disabilities annually and serves as an advocate for persons with disabilities throughout Pennsylvania.

The United Cerebral Palsy Association of Philadelphia & Vicinity is an organization that has served children with a diverse variety of disabling conditions for over forty years.

The American Council of the Blind Parents, part of the American Council of the Blind, is an organization dedicated to providing services and advocating for the needs of persons who are blind or visually impaired.

Pennsylvania Council of the Blind, an affiliate of the American Council of the Blind, is a chartered organization for the social and economic advancement of persons who are blind or visually impaired.

The ASAP Coalition of Autism Society of Pennsylvania is a coalition of local chapters of the Autism Society of America and of individuals that is designed to enhance the knowledge and strength of local chapters through statewide networking and to provide autism support and advocacy in Pennsylvania.

The Sickle Cell Genetic Disease Council of Southeastern Pennsylvania is an agency that advocates for persons who are affected with sickle cell anemia, along with their families.

Parents Involved Network is a parent-run network of parent groups across Pennsylvania that engage in self-help, advocacy, training, and education for parents of children and adolescents who have emotional or behavioral disorders.

Media Child Guidance is a community agency that provides outpatient mental health services and coordinates services for persons with mental retardation.

Erie Independence House is a community based organization that is managed and staffed by persons with disabilities for the purpose of assisting other persons with disabilities to attain and/or maintain their independence.

Millcreek and Erie County Advocates is a family and consumer organization that has ad-

vocated with and for Erie County citizens with disabilities for over sixteen years.

Down Syndrome Today is a support, advocacy, and resource group in Beaver County, Pennsylvania for persons with Down's Syndrome, their parents, and professionals.

#### ARGUMENT

THE SECRETARY HAS VIOLATED CONGRESS' MANDATE THAT CHILDREN WHOSE DISABILITIES ARE "OF COMPARABLE SEVERITY" TO THOSE OF DISABLED ADULTS RECEIVE SSI BENEFITS.

- I. The Secretary's Regulations Impose Far More Restrictive Standards For Determining Disability On Child Claimants Than On Adults.

In 1972, Congress enacted the Supplemental Security Income program, P.L. 92-603, 86 Stat. 1329 (1972), to provide one federally-coordinated benefits program for aged, blind, and disabled persons with limited incomes. As the House Report stressed, Congress was particularly concerned with the needs of poor, disabled children:



It is your committee's belief that disabled children who live in low-income households are among the most disadvantaged of all Americans and that they are deserving of special assistance in order to help them become self-supporting members of our society. H.R. Rep. 231, 92d Cong., 2d Sess. 1, 147-48, reprinted in 1972 U.S. Code. Cong. & Ad. News 4989, 5133-34.

For these reasons, Congress made the standard for determining disability in children the same as that for adults. The statute provides:

An individual shall be considered to be disabled for purposes of this subchapter if he is unable to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of twelve months (or, in the case of a child under the age of 18, if he suffers from any medically determinable physical or mental impairment of comparable severity). 42 U.S.C. § 1382c(a)(3)(A) (emphases added).

Congress did not prescribe an exact method for determining when a child's disability is "of comparable severity" to that of a disabled adult, but, rather, empowered the

Secretary to establish regulations and procedures "not inconsistent" with the statute. 42 U.S.C. § 405(a), as made applicable to the SSI program by 42 U.S.C. § 1383(d)(1) (emphasis added).

However, the disability evaluation process for children that the Secretary has developed is flatly inconsistent with the statute and, in fact, results in the denial of SSI benefits to children with disabilities comparable to those of adults, thereby violating Congress' explicit mandate under the Social Security Act. See Mohasco Corp. v. Silver, 447 U.S. 807, 825 (1980) (agency's interpretation of statute as reflected in regulation "cannot supersede the language chosen by Congress").

To ascertain whether an adult claimant is disabled and therefore eligible for SSI (assuming satisfaction of the income requirements), the Secretary utilizes a comprehensive, two-tiered process. See generally Bowen v. Yuckert, 482 U.S. 137, 140-42 (1987). On



the first tier, the Secretary initially determines whether the adult is engaged in any substantial gainful activity. 20 C.F.R.

§ 416.920(a). If the adult claimant is not engaged in any substantial gainful activity, then the Secretary evaluates whether his or her impairment is "severe." 20 C.F.R.

§ 416.920(c).<sup>4</sup> If it is, then the Secretary ascertains whether the adult's impairment meets or equals<sup>5</sup> an impairment described in the Listings. 20 C.F.R. §§ 416.920(d), 416.926. If an adult claimant's impairment meets or equals one of the Listings, he or she is conclusively presumed to be disabled and is awarded SSI benefits. See id.; see also Yuckert, 482 U.S. at 141.

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4. It is this second step, involving the so-called "severity regulation," and the Secretary's application thereof, that led to extensive litigation in the earlier part of this decade, culminating with this Court's decision in Bowen v. Yuckert, 482 U.S. 137 (1987).

5. The concept of equivalence is discussed infra at 34-35.

The Listings enumerate particular conditions, signs, and symptoms of certain impairments that, without any further evidence of impaired functioning capacity, justify a conclusion that the person is disabled. See 20 C.F.R. §§ 404.1520(d), 416.920(d), 416.925(a). Thus, they provide an administratively efficient method to shorten the evaluation process for SSI applicants who have impairments that are usually disabling. See Zebley, 855 F.2d at 773; see also Marcus v. Bowen, 696 F. Supp. 364, 373-76 (N.D. Ill. 1988) (providing a historical review of the Listings, and concluding that "they were never intended to be used as a basis for denial of disability benefits").

Recognizing that persons with non-"listed" impairments may nonetheless be disabled, the Secretary provides that adult claimants who do not meet or equal a particular Listing may still be eligible for SSI benefits. In such cases, the Secretary applies the next tier of the process -- an assessment

of the adult claimant's "residual functional capacity" ("RFC"). See 20 C.F.R. § 416.920(e). See also Heckler v. Campbell, 461 U.S. 458, 460 (1983); Yuckert, 482 U.S. at 141.

The RFC evaluation is an assessment designed to measure the actual degree of functional impairment of the individual based on, inter alia, descriptions, observations, and professional evaluations of conditions, signs, and symptoms other than those included in the Listings. 20 C.F.R. § 416.945(a). The RFC determination focuses primarily on the adult claimant's medical condition and, to a lesser extent, on the ability of the adult claimant to work. See Marcus, 696 F. Supp. at 381.

This two-tiered approach for determining disability in adults by which the Secretary considers both the Listings and the ability of an adult claimant to function stands in marked contrast to the process utilized for children. Disability in children is determined using only the first tier of the process used for adults, i.e., an assessment of whether the

child is engaged in substantial gainful activity, whether the child's impairments are severe, and whether the child's impairments meet or equal the requirements of one of the Listings. 20 C.F.R. § 416.924.

If the child's impairments are not among those included in the Listings, then he or she is automatically denied benefits -- regardless of the severity of the child's actual functional limitations resulting from single or multiple impairments, and regardless of any subjective factors. In short, the Secretary determines whether or not a child claimant is disabled without any individualized consideration of that child's actual ability to function.

As we will demonstrate in the next section, the result of the Secretary's process is that only a subgroup of children whose disabilities are comparable to those of adults are identified. Other disabled children, in blatant violation of the statutory mandate, are simply denied benefits.

II. The Abbreviated Evaluation Process  
Accorded To Child Claimants Fails  
To Identify Many Children Whose  
Disabilities Are "Of Comparable  
Severity" To Those Of Adults.

A. The Listings Are Inherently  
Underinclusive.

The Secretary's single-tiered evaluation process for determining disability in child claimants fails to identify many disabled children who would be eligible for SSI if the Secretary applied the full two-tiered process used for adults. By providing for a two-tiered process for adults, the Secretary has recognized that the Listings are neither adequately flexible nor sufficiently comprehensive to identify SSI claimants who are disabled under the statutory standard. Indeed, the Secretary has expressly acknowledged that the Listings "are intended to identify the more commonly occurring impairments shown in applications for Social Security disability benefits," and that "[t]he Listing is but one item in the evaluation process." 44 Fed. Reg. 18175, 18176 (1979). As the court of appeals



in Zebley recognized, "[t]he listings . . . do not purport to be an exhaustive compilation of medical conditions which could impair functioning to the extent necessary to satisfy the statutory standard for [dis]ability." Zebley, 855 F.2d at 73. See generally H. Fox & A. Greaney, Disabled Children's Access to Supplemental Security Income and Medicaid Benefits, at 42-67 (December 1988) (hereinafter "Fox & Greaney").

In fact, the Listings are inherently underinclusive; no set of Listings could possibly be sufficiently comprehensive to encompass all disabling conditions. Moreover, the Listings do not -- and indeed cannot -- take into consideration the effect of multiple impairments, none of which alone meets or equals a listed impairment, but which in combination render a person functionally disabled. See 20 C.F.R. § 416.926. As illustrated by the cases described infra at 36-47, many children who have a combination of impairments and are significantly disabled are routinely denied SSI

benefits. The inability of the SSI child disability determination process to take into account the impact of multiple impairments has been consistently identified as one of the most troublesome aspects of the system. See Fox & Greaney, at 54 (noting that unpublished data from members of the American Academy of Pediatrics Committee on Children with Disabilities reveals that increasing numbers of children have complex medical conditions that involve as many as five or more different diagnoses). Additionally, the Listings do not reflect subjective aspects of an individual's impairment, such as pain, dizziness, or the effects of medication.<sup>6</sup> The only suitable method by which such fundamental factors can

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6. In fact, Social Security Administration policy affirmatively precludes consideration of subjective factors. See SSA Program Operation Manual System § DI 24501.025 ("[n]o alleged or reported intensity of the symptoms can be substituted to elevate impairment severity to equivalency") (emphasis deleted) (Jt. App. at 255).



be taken into account is through the use of a functional assessment.

By confining the analysis of children's disabilities to the Listings, the Secretary ensures that low-income children with multiple or unusual disabilities will be denied crucial income supplements. As one administrative law judge lamented in the case of Christine T., discussed infra at 37-38, where a child suffers from multiple impairments that fall "between the cracks" of the Listings, Social Security Administration policy precludes the granting SSI benefits.

B. The Listings Are Even More Under-  
inclusive For Children Than They  
Are For Adults.

In addition to the problems resulting from the inherent underinclusiveness of the Listings, the existing Listings violate 42 U.S.C. § 1382c(a)(3)(A) because they are in fact even more underinclusive for children than they are for adults, rendering it all the

more remarkable that they are the only avenue open to children to prove disability.

First, the Listings contain inadequate provisions for children who might be too young to be tested for various symptoms, but who are significantly disabled. See generally Fox & Greaney, at 54. For example, the section of the children's Listings governing deficits of musculoskeletal function requires that the child manifest either a need for assistance in ambulation, or an inability to feed and dress himself or herself. 20 C.F.R. Part 404, Subpart P, App. 1, Part B, § 101.03 (Jt. App. at 209-10). Certainly, an infant or young child cannot be tested in either of these areas. Similarly, Listings that require IQ tests or measurements of interference with communication, see, e.g., 20 C.F.R. Part 404, Subpart P, App. 1, Part B, § 111.02, § 111.07 (major motor seizures and cerebral palsy, respectively) (Jt. App. at 229, 230) are difficult, if not impossible, for infants or very young children to meet because such children

cannot realistically be tested in these areas. Thus, these children will be deemed ineligible for SSI.<sup>7</sup>

Second, the Listings completely omit certain childhood impairments, such as narcolepsy and other sleep disorders, spina bifida, Tourette Syndrome, Down's Syndrome, and Prader-Willi Syndrome.<sup>8</sup> See Marcus, 696 F. Supp. at 381. A child who has one of these

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7. In at least one Listing -- that for central visual acuity -- the Secretary has recognized that the Listing's test is inappropriate for children under six months of age and, in fact, has prohibited the test from being applied to such children. However, the Secretary has not provided any alternative method by which a young child can meet that Listing. See 20 C.F.R. Part 404, Subpart P, App. 1, Part B, § 102.00A, § 102.02 (Jt. App. at 210-11).

8. Tourette Syndrome is characterized by motor incoordination, involuntary word repetition, and involuntary utterance of vulgar or obscene words. Down's Syndrome is a chromosomal disorder that results in mental retardation and a constellation of physical anomalies. Prader-Willi Syndrome is a congenital syndrome characterized by short stature, mental retardation, excessive eating, marked

(Footnote continued)

impairments will be denied benefits unless the child's impairment can somehow be made to fit within an existing Listing.

In addition, many of the adult Listings (which are to be used in the absence of an analogous Listing for children, see 20 C.F.R. § 416.925(b)(1)) are incapable of being applied to children. For example, the adult Listing for obesity contains height and weight charts beginning at sixty inches tall for men and fifty-six inches tall for women. 20 C.F.R. Part 404, Subpart P, App. 1, Part A, § 10.10 (Jt. App. at 169-73). Because there is neither a corresponding children's Listing for obesity nor a corresponding table for a child's lower height (not to mention a child's different build), a young child who is obese

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(Footnote continued)

obesity, and sexual infantilism. See Stedman's Medical Dictionary (5th ed. 1982).

will simply be denied benefits. See also 20 C.F.R. Part 404, Subpart P, App. 1, Part A, § 8.00 (all skin disorders) (Jt. App. at 166-67); § 11.09 (multiple sclerosis) (Jt. App. at 178); § 11.13 (muscular dystrophy) (Jt. App. at 178) (see discussion of the case of Jason E., infra at 44-46); § 11.16 (pernicious anemia) (Jt. App. at 179).

C. An Evaluation Of The Functional Capacity Of Child Claimants Is Essential.

The inherent inadequacies of the Listings can be remedied, as they are for adults, by employing an evaluation of the child's functional impairment. See Yuckert, 482 U.S. at 146 (Social Security Act requires a "functional approach to determining the effects of medical impairments"); see also 42 U.S.C. § 1382c(a)(3)(G) (emphasis added) ("the Secretary shall consider the combined effect of all the individual's impairments").

At the outset of the SSI program for children, the Secretary recognized the impor-



tance of assessments based on functional factors, rather than on Listings alone. He emphasized that "disability in children must be defined in terms of the primary activity in which they engage, namely growth and development, the process of maturation," and that "[d]escriptions of a child's activities, behavioral adjustment, and school achievement [are] important in determining the severity of the impairment." SSA Disability Insurance Letter No. III-11 (Jt. App. at 90-91).

Nevertheless, as explained in Fox and Greaney's recent report on disabled children's access to SSI, the absence of regulations permitting the Social Security Administration to assess a child claimant's functional capacity has resulted in the unavailability of SSI benefits to many disabled children:

The majority of our expert reviewers indicated their concern about the Listing's lack of attention to functional impairment. They stressed that the same medically defined condition may affect different children in different ways: for some children, a less serious condition may render them functionally incapacit-

ated. . . . The impact of a given impairment on a child's ability to carry out daily activities is dictated by a variety of factors. These include age of onset, emotional and cognitive capacities, and family support and resources -- none of which are addressed in the disability criteria for children. Fox & Greaney, at 60-61.

The Secretary has an obligation to develop a standard by which to measure the ability of a child to function. That measurement should include, at minimum, a determination of whether the child can carry out daily activities on an age-appropriate level. Such a functional analysis, as anticipated by the Court in Zebley, would be based upon medical findings. An assessment of functional capacity would also take into account, inter alia, subjective factors and combinations of impairments and, thus, would cure the existing inherent defects of the Listings-based approach currently used to assess disability in child claimants.

While the Secretary has expressed concerns about the feasibility of engaging in an



individualized assessment of a child's functioning, those concerns are ill-founded, if not disingenuous. First, it is the Secretary's statutory responsibility to determine disability. Even if such individualized, functional assessments were more difficult to make, this factor would not relieve him of that obligation. Moreover, the agency has had ample experience in engaging in the precise type of individualized assessment required.<sup>9</sup>

In addition, the Secretary has recently proposed new Listings for Mental Disorders in

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9. Under the Title II Child's Disability Insurance Benefit Program, 42 U.S.C. § 402(d), the Secretary applies the full two-tiered evaluation process to assess disability in a dependent person who is claiming benefits based on an impairment that was disabling before the age of 22. See Allegra v. Bowen, 670 F. Supp. 465 (E.D.N.Y. 1987); Hawkins v. Heckler, 631 F. Supp. 711 (D.N.J. 1985). Indeed, the Secretary has previously acknowledged that experience drawn from the Title II Disability Program would assist in the implementation of the SSI program. See SSA Disability Insurance Letter No. III-11 (Jt. App. at 89).

Children, see 54 Fed. Reg. 33238 (August 14, 1989), which, in fact, incorporate some of the very same functional criteria that the Secretary has previously asserted are either irrelevant to a determination of whether a child is disabled or overly-cumbersome to apply. Compare Sullivan v. Zebley, Brief for the Petitioner, at 40 (citations omitted) ("developmental needs - e.g., counseling, special education, training, rehabilitation, and guidance - are not considered as such, 'because they are not within the scope of the law'") with 54 Fed. Reg. at 33243 ("school records are a rich source of data;" "appropriate historical, social, medical and other information must be reviewed").

At the very least, the Secretary's inclusion of functional evidence in the proposed Listings for mental disorders indicates a fundamental inconsistency in his position. There is certainly no rational reason why children with mental disorders should receive a func-

tional assessment of their disability while children with other impairments do not. It is no less feasible to analyze the functional limitations of children with physical, rather than mental, disorders. Thus, an evaluation of the functional capacity of child claimants not only is statutorily mandated, but also, by the Secretary's own admission, is administratively feasible.<sup>10</sup>

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10. It should also be noted that, even though some of the proposed regulations may apply a function-based evaluation, that analysis is still much more restrictive than that applied to adults. Many of the proposed Listings require that functional limitations be evaluated solely within the parameters of each individual Listing. Thus, once a child has proven that he or she meets the medical criteria for one of the impairments, he or she must also demonstrate that that impairment results in functional limitations. See, e.g., Proposed Listing 112.00, 54 Fed. Reg. at 33241 ("The functional restrictions ... must be the result of the mental disorder which is manifested in the clinical findings"). See also Proposed Listings 112.02, 112.03, 112.04, 112.06, 112.07 and 112.09, 54 Fed. Reg. at 33243-33245.

D. The Secretary Has Failed To Devise Any Method To Assess Adequately The Functional Capacity of Child Claimants.

None of the means devised by the Secretary provides a satisfactory method by which to ensure that there is an individual analysis of the ability of disabled children to function in an age-appropriate manner. In the past, the Secretary expressly acknowledged that the Listings are underinclusive as applied to children, stressing that:

Not all children's impairments will lend themselves to formal codification. We are aware that a significant number of children are impaired in their intellectual, social, and emotional development progression by problems of learning and/or behavior. These conditions may be ill-defined and imperfectly understood. 1974 Disability Insurance Letter No. III-11, Supplement 1 (Jt. App. at 97-98).

Although a few of the Listings define impairments in functional terms, a point the

Secretary now understandably emphasizes,<sup>11</sup> the Listings generally rely on specific diagnostic criteria that exclude clinically observable functional indicia that the medical profession commonly includes in its assessments of disabilities. See 42 Fed. Reg. 14705 (1977) (childhood Listings "interpret[] severity in medical rather than functional terms.").

Moreover, the Secretary expressly prohibits the decisionmaker from taking the child claimant's level of functional limitation into account in determining whether the child's impairment "meets" a Listing. As the Secretary has directed:

The "level of severity" of impairments in the listing is not defined

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11. The Secretary, however, conceded in his certiorari petition that only "some of the Secretary's listings in Part B specifically call for a general assessment of a child's functional capacity." Newman v. Zebley, Petition for a Writ of Certiorari to the United States Court of Appeals for the Third Circuit, at 12 (emphasis added).



in terms of the residual functional capacity (RFC) of the individual. When certain functional limitations are specified for a listed impairment, they relate only to that degree of dysfunction for that particular listing section and only to the specific function identified. SSA, Program Operations Manual System (POMS), § DI 24505.015(B) (emphasis in original) (Jt. App. at 248).

As a so-called alternative to meeting a listed impairment, an SSI applicant may establish that his or her impairment "equals" a listed impairment. 20 C.F.R. § 416.920(d); § 416.924(b). Because the Secretary's definition of equivalence is extremely narrow, the equivalence standard, like the Listings themselves, is incapable of identifying many children whose impairments are of comparable severity to those of adults.

Equivalence to a listed impairment is based strictly on a very narrow notion of medical findings that is void of functional criteria. 20 C.F.R. § 416.926(b). Indeed, since 1980 the Secretary has expressly proscribed consideration of the functional consequences of impairments in determining equiva-

lence. See Social Security Ruling (SSR) 83-19 ("[t]he functional consequences of the impairments, (i.e., RFC), irrespective of their nature or extent, cannot justify a determination of equivalence") (emphasis in original) (Jt. App. at 240); see also Zebley, 855 F.2d at 74. In addition, the equivalence standard does not allow for consideration of the combined effect of impairments. See SSR 83-19 ("[t]he mere accumulation of a number of impairments . . . will not establish medical equivalence.") (Jt. App. at 240).<sup>12</sup>

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12. Amici are of the opinion that the Secretary's children's disability regulations violate the provisions of the Disability Benefits Reform Act of 1984, P.L. 98-460, 98 Stat. 1794, which requires that the Secretary consider the "combined effect" of all of a claimant's impairments, 42 U.S.C. § 1382c(a)(3)(G), as well as "all evidence" in the claimant's case record, 42 U.S.C. § 1382c(a)(3)(H). We agree with the court of appeals that these requirements would be satisfied if the Secretary were to comply with the statutory mandate and perform functional, individualized assessments of children comparable to those performed for adults. Zebley, 855 F.2d at 76.

E. Numerous Severely Disabled Children Have Been And Will Continue To Be Denied SSI Benefits Due To The Secretary's Refusal To Assess Their Functional Capacity.

The Secretary's process for determining disability in children works significant hardships on impoverished children with disabilities who must often go without needed medical and social services when their SSI applications are denied.<sup>13</sup> The following examples are representative of children in Pennsylvania whose SSI claims have been rejected by the Secretary based upon his conclusion that such children are not disabled within the meaning of the statute.

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13. Under Pennsylvania law, eligibility for Medicaid is tied to SSI eligibility. See 55 Pa. Code § 297.4(w)(4). Thus, the implications of the SSI determination are far-reaching and the financial consequences of being found ineligible for SSI can be devastating.

-- Christine T. was five years old at the time she was found not eligible for SSI. Christine has been diagnosed as severely hyperactive with a guarded prognosis. She also has an attention deficit disorder, an expressive speech delay, delayed fine motor-adaptive skills, and a very short attention span. Although placed on an unusually high dose of medication, Christine continues to manifest unmanageable, disruptive, impulsive, and hyperactive behavior. For example, during the administrative hearing, Christine left her chair, climbed underneath an examination table, constantly moved about the room, and even triggered a fire alarm outside of the room.

The Administrative Law Judge ("ALJ") determined that Christine has a behavioral problem, a behavioral communication disorder, and is extremely hyperactive. However, because she does not have either a specific psychiatric disorder or an organic disability, her impairments were deemed not to meet or equal any of the Listings. The ALJ also noted that

an impartial medical advisor at the administrative hearing testified that Christine's disorder fell "between the cracks" of the Listings, and that Social Security Administration policy precluded him from considering any criteria other than those actually detailed in the Listings.

-- Michael R. was six years old at the time he was denied SSI benefits. Michael has had a life-long history of severe neurological and emotional impairments. Michael has been diagnosed as having, among other impairments, organic brain syndrome, a seizure disorder, a learning disability, attention deficit disorder/hyperactivity, multiple personality disorder, mental retardation, and impulse control disorder.

Michael's impairments have profoundly and adversely affected his education; indeed, his teachers have noted that his temper tantrums, impulsive and explosive behavior, and inability to follow directions are incompatible with an educational setting. Furthermore,



Michael has been diagnosed as functioning at the level of a three to four year old and, consistent with this diagnosis, has repeatedly demonstrated non-age-appropriate behaviors. For example, Michael is not capable of dressing himself or brushing his teeth and does not interact with children his own age. Additionally, Michael has devastating psychological problems that manifest themselves in ways ranging from fighting with others to hearing voices telling him to harm himself and others to overtly suicidal behavior such as climbing out on a window ledge, tying a sheet around his neck, and trying to cut himself with a knife. In fact, at one point Michael's behavior became so uncontrollable that he was hospitalized at the Eastern Pennsylvania Psychiatric Institute.

The ALJ concluded that Michael's impairments, "while severe", did not meet or equal a Listing. The ALJ determined that although Michael had an IQ of 64, he had no other phys-

ical or mental impairment sufficient to meet or equal the Listing for mental retardation.

-- Dean O. was two years old at the time he was found ineligible for SSI benefits. Dean has a breathing problem, spina bifida, conjunctivitis of the eyes, digestive problems, chronic nonspecific diarrhea, a learning disability, anemia, hyperactivity, and developmental delay. Additionally, Dean suffers from a sensory integrative dysfunction which includes delayed speech, clumsiness, tactile defensiveness, and distractibility. Dean's breathing problem, which he has had since birth, has included one episode of apnea, for which a monitor was prescribed. In addition, Dean has been hospitalized on numerous occasions, once at six weeks of age for pneumonia, and on several other occasions for episodes of dehydration accompanied by vomiting and diarrhea. Furthermore, Dean has been described as a destructive child who bites himself and goes after knives. The ALJ concluded that, while Dean has physical problems, as well as mental

and motor delay, those impairments did not meet or equal a Listing.

-- Henry R. was eleven years old at the time he was found ineligible for SSI benefits. Henry has oppositional disorder, attention deficit disorder, visual-motor and perceptual dysfunctions, and hyperactivity. His visual-motor coordination is so poor that, at almost eleven years of age, his ability to draw geometrical designs was at the level of a five year old. Henry's IQ test scores have varied between 49 and 78. He has marked difficulties in maintaining social functioning, deficiencies in concentration, extremely low frustration tolerance, and is emotionally withdrawn. He is an intentionally provocative, passive-aggressive, angry, and highly distractible child, who gets into fights with his peers and siblings.

As a result of the variation in Henry's IQ scores, the ALJ concluded that Henry did not meet the listed impairment for mental retardation. In particular, the ALJ deter-

mined that the lower IQ scores did not accurately reflect Henry's IQ because Henry's behavioral problems, such as his passive/aggressive attitude, poor attention, and nervousness, interfered with the testing. However, the ALJ discounted evidence that Henry's behavioral problems imposed an additional limitation on him that would meet or equal a Listing and concluded that Henry's lack of attention was selective and voluntary and that his nervousness could be treated with medication.

-- Shawn K. was ten years old when he was found ineligible for SSI benefits. Shawn is a child with borderline intelligence, attention deficit disorder, hyperactivity, psycholinguistic deficit, delay in visual-motor coordination, and chronic enuresis (bedwetting). Shawn's IQ scores range from a low of 70 to a high of 92. Shawn has been placed in a special education classroom, attends speech therapy classes, and requires intensive instruction in fine motor skills.

Shawn's teachers report that his behavior in the special education classroom is unsatisfactory, and that he is disruptive and inattentive. Shawn needs much one-on-one supervision due to his short attention and memory spans and his problems following directions. Shawn's hyperactivity has not been controlled by medication; he is constantly running and jumping, cannot sit still, and is extremely impulsive. Furthermore, Shawn is fascinated by fire and has been known to set fires. For example, when Shawn was playing with a fire truck in his bedroom, he decided that he needed a fire, and so he set one, destroying all of his belongings.

The ALJ determined that Shawn did not meet the Listing for mental retardation because his IQ of 70 was one point above that required by those Listings. Although a Medical Advisor had testified that the one point differential was neither meaningful nor significant, and that the only reason Shawn would not meet the Listing was due to a technicali-



ty, the ALJ considered himself bound by the letter of the Listings. Therefore, the ALJ did not even consider Shawn's attention deficit disorder, hyperactivity, poor attention span, bedwetting, or other problems.

-- Jason E. was five years old when he was found ineligible for SSI benefits. Jason has muscular dystrophy, a progressively degenerative and eventually fatal muscular disease. At the time he was denied benefits, Jason's impairment manifested itself through a speech disturbance, moderate muscle weakness, gait abnormality, decreased muscle tone, atrophy of the proximal muscles, and hypertrophy. Jason's eye muscles and mouth and vocal chord muscles were also affected by his impairment. Furthermore, Jason experienced difficulty in walking because of cramps and weakness in his legs. At the time he was denied benefits, Jason could not climb stairs, run, pedal a bicycle, or walk in excess of a city block, and he frequently fell. Moreover, Jason could

not control a pencil or endure a full day in kindergarten due to exhaustion.

There is no children's Listing for muscular dystrophy. The ALJ therefore applied the Listing for deformity or musculoskeletal disease, which requires both deformity or musculoskeletal disease and one of the following: (a) "walking is markedly reduced in speed or distance despite orthotic or prosthetic devices"; (b) "ambulation is possible only with obligatory bilateral upper limb assistance (e.g., with walker, crutches)"; or (c) "inability to perform age-related personal self-care activities involving feeding, dressing, and personal hygiene." 20 C.F.R. Part 404, Subpart P, App. 1, Part B, § 101.03 (Jt. App. at 209). Applying these criteria to Jason, the ALJ determined that Jason could walk in an unassisted fashion for at least short distances, thereby failing to meet the requirements of § 101.03(A); that he did not yet require any assistive devices for ambulation (although it was clear that he would require

them), thereby failing to meet the requirements of § 101.03(B); and that he was basically independent in self-care activities, thereby failing to meet the requirements of § 101.03(C).

-- Jason S. was six months old when he was initially found not eligible for SSI, and a year old when his second SSI application was denied. Jason has spina bifida, a birth defect affecting the lower portion of his spine, which impairs his ability to walk, as well as his bowel and bladder functions. Additionally, Jason's vocal chords are paralyzed, which creates overwhelming problems for him in swallowing, breathing, and speaking. He also has Arnold Chiari malformation, a displacement of the hind brain into his spinal canal.

-- Brandi R., who is now twelve years old, has Tourette Syndrome, a neurological movement disorder, was also denied SSI benefits. As a result of her impairment, Brandi experiences motor control problems, a severe

attention deficit disorder, and behavioral disorders.

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These and other exclusions of seriously disabled children from benefits of the SSI program are inevitable under the current regulations. The Secretary's truncated, Listings-confined approach by definition prevents a substantial number of low-income children with significant functional disabilities from receiving the benefits that Congress intended them to have.

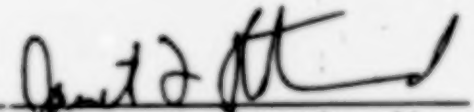
#### CONCLUSION

The single-tiered, Listings-confined process that the Secretary utilizes to determine whether a low-income child is disabled for purposes of eligibility for SSI benefits violates the mandate of Congress. The Secretary's regulations deny children the same opportunity afforded adults to demonstrate the disabling functional effects of their

impairments. Accordingly, Amici Curiae respectfully urge the Court to affirm the order of the court of appeals.

Respectfully submitted,

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